OPINION ARTICLE

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FAIR Practices in Africa

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ABSTRACT

This article investigates expansion of the Internet of FAIR Data and Services (IFDS) to Africa, through the three GO FAIR pillars: GO CHANGE, GO BUILD and GO TRAIN. Introduction of the IFDS in Africa has a focus on digital health. Two examples of introducing FAIR are compared: a regional initiative for digital health by governments in the East Africa Community (EAC) and an initiative by a local health provider (Solidarmed) in collaboration with Great Zimbabwe University in Zimbabwe. The obstacles to introducing FAIR are identified as underrepresentation of data from Africa in IFDS at this moment, the lack of explicit recognition of situational context of research in FAIR at present and the lack of acceptability of FAIR as a foreign and European invention which affects acceptance. It is envisaged that FAIR has an important

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contribution to solve fragmentation in digital health in Africa, and that any obstacles concerning African participation, context relevance and acceptance of IFDS need to be removed. This will require involvement of African researchers and ICT-developers so that it is driven by local ownership. Assessment of ecological validity in FAIR principles would ensure that the context specificity of research is reflected in the FAIR principles. This will help enhance the acceptance of the FAIR Guidelines in Africa and will help strengthen digital health research and services.

1. INTRODUCTION: EXPANDING THE INTERNET OF FAIR DATA AND SERVICES FOR DIGITAL HEALTH TO AFRICA

The next generation of the development of a machine- and human-readable IFDS is based on the guidelines for data-stewardship as Findable, Accessible, Interoperable and Re-usable (FAIR) [1]. The FAIR principles do not provide a standard as such, but rather constitute a context and a direction to help facilitate the re-use of data for science and services, referred to as guiding principles [2].The essence is that digital data should be machine-readable and that human readable narratives should be supplementary [2]. Data as a digital object exist in a repository or on the internet as a digital entity or object that can be parsed by different information systems [2]. While a standard would create obstacles to implementation because of inflexibility, FAIR "simply describes the qualities or behaviours that would be required of open science resources to achieve, possibly incrementally, their optimal discovery and scholarly reuse." [2]

The implementation of FAIR is supported by the GO FAIR Implementation Networks. This recognises the dynamic process of its construction [3]. The GO FAIR International Support and Coordination Office (GFISCO) supports the Implementation Networks (INs): "a consortium committed to defining and creating materials and tools as elements of the Internet of FAIR Data and Services (IFDS)" [4]. Implementation Networks are implementation communities in which FAIR principles can be mutually developed and adapted to the needs of the group it represents and these Implementation Networks constitute "the core participants of the GO FAIR initiative" [4]. The implementation of GO FAIR is structured around three activities: changing stakeholders (GO CHANGE), building FAIR technology (GO BUILD) and training participants to use FAIR (GO TRAIN) [4].

An analysis of the INs of GO FAIR to date demonstrates a geographic bias of implementation in Europe, reflecting perhaps the leadership provided to it by the European Commission. Comparative literature review of a hundred articles citing FAIR principles, published in the period 2016–2019, shows the current delay in Africa on FAIR-implementation, and its overwhelming concentration centred in Europe and the US [3]. Analysis of domain areas addressed both in INs and in the hundred journal articles reporting on FAIR implementation and analysed in a literature review showed a clear focus on implementation in the life sciences and natural sciences. Indeed, the one report included in the literature review on implementation in Africa focused on health, specifically digital health [3].

2. DIGITAL HEALTH IN AFRICA

In Africa, the starting point on FAIR implementation occurs in the field of Digital Health Care. Digital Health policies are being implemented by African governments in collaboration with international organisations and the private sector to overcome structural problems in health services. Despite such efforts, digital health initiatives in Africa suffer from limited grounding on principles of sustainability, co-knowledge building and sharing between researchers and across relevant institutions and actors working on health. While hundreds of pilots on digital health are being implemented, many efforts are of short duration and there is a general failure to integrate efforts that are long-term and sustainable [5]. The ITU/WHO [6] and the Broadband Commission [7] point to lack of policy coordination with and inside governments. Krah and De Kruiff [8] find in a literature review of a hundred articles (2005–2015) that sustainability is limited due to technology-related issues and problems related to insufficient contextual understanding. Krah and De Kruijff further find that the limitations due to fragmentation of efforts result in a lack of scalability. Van Reisen [5] notes the lack of involvement of communities as well as digital data-driven health solutions that are, at times, poorly adapted to the local context and lack ownership.

The uptake of FAIR in Africa is important. Cornel [9] states that people from Africa and Latin America benefit less from genetic research than the European population. This is because they participate less in such research, and therefore more diversity is urgently needed to increase academic quality, representativity and correct inference, according to Sirugo et al. [10]. This article investigates the current state of the art of implementation of FAIR in Africa. It particularly engages with the question: Why has the uptake of FAIR in Africa been slow, despite the need, and what obstacles may explain this? We will discuss this on the basis of two case studies where digital health is introduced, one in East Africa at regional level including six countries and one in Southern Africa, in Masvingo province in Zimbabwe.

3. INTEGRATING FAIR PRINCIPLES IN DIGITAL HEALTH

Specifically recognising the need to enhance data reuse, the East Africa Community has included FAIR as a tool to "develop and promote regional principles on data sharing (e.g., based on FAIR principles, shared cloud services, etc.) and digital tool design (e.g., mobile first)" [11] and the establishment of the East Africa Open Science Cloud for Health (EAOSCH) which will be "a real-time regional data warehouse for capturing, storing, retrieving, analysing, and managing national and regional health in East Africa" [11]. This will support the establishment of "a supporting structure for the seamless sharing of health data across EAC Partner States" [11].

The EAOSHC is driven by the regional body of the East Africa Community, governed by the East African member states. The initiative is focused on demonstrating the advantages of common approaches towards data-interoperability and reuse across the region and specifically across borders. The first initiative recorded on FAIR in Africa, introduces FAIR from a regional perspective, especially focusing on cross-border health service challenges, with a view to creating interoperability of data across (African) borders. This initiative

builds on the Cross-Border Health Initiative [12]. The key focus in this initiative is complex data accessibility and use of analytics for regional policy application across various policy sovereignties.

The EAOSCH has identified FAIR as an enabler of regional health information for practitioners and as a potential vehicle to integrate availability of patient-related data for health-workers in health clinics in Cross Border areas. While designed in specific Cross Border locations, the efforts for data-reuse are part of an effort of Ministries of Health in the region to move towards common approaches of using and retaining data. The pillars of GO FAIR (GO CHANGE, GO BUILD, GO TRAIN) provide a common framework for doing so.

However, the development of a FAIR Data Point (FDP) is challenging. The East Africa Health Research Commission, responsible for the region's health policy, is operating in different policy sovereignties on health, ICTs and data. From participation in the programme development, the following challenges are noted by researchers: weak integration of ministerial responsibilities for ICTs, digital data and health (GO BUILD); limited legal frameworks and enforcement regarding data ownership (GO CHANGE); limited education and training of experts in these fields (GO TRAIN); dependency on short-term external finance with limited autonomy; dominance of foreign actors and health service providers with their own rules and regulations and interests on data stewardship (GO CHANGE); practices of data extraction to clouds in Western hemispheres and lack of analytical capacity at national level, affecting confidence in digital data as a basis for health advice (GO CHANGE). The challenges noted above capture a concern about governance of digital health, with potential implications in terms of politics and health policy, the role and relationships between government, research and industry, and the position of health users (protection of sensitive and personal data).

A second initiative focuses on a locally-driven initiative in the Masvingo province of Zimbabwe and is driven by needs of local hospitals and communities with technical support offered by Solidarmed [13] and Great Zimbabwe University focusing on establishing a local FDP. The data ownership, data security and Health Ministry's oversight are critical elements of the Masvingo FAIR Data point. This initiative makes use of the fact that FAIR is a flexible guideline, and that FAIRness is an assessment of degree of implementation of the guidelines. The guidelines provide for translation towards definitions that flexibly adapt to different communities of participation at different levels – from local to national and sub-national level. In this context, the researchers who were included in the development of the FDP noted, among others, difficulties related to GO CHANGE; the different perceptions of health care associated with local customs and belief-systems; the limited trust in Western health medical health systems and based on different and incompatible world views [14, 5] and declining confidence in systems developed in a Western context [15], including those based on digital data.

4. THE RELEVANCE OF CONTEXT

FAIR-implementation of digital health data has been identified as a way of overcoming the challenges caused by fragmentation and lack of data integration. FAIR gives a direction in which new practices can

be developed [2, 3], thus (i) data should serve the public interest and should be governed by public policy; (ii) data-driven science should expand the collective knowledge, (iii) science should serve practical solutions and services, and (iv) a scrutiny by and involvement of citizens and general public in knowledge discovery will democratise science and its use for services [2]. However, we question the ability of GO FAIR to (currently) respect contextual understanding, since in its present form, it heavily leans on a (neo-)positivistic paradigm of science that puts generalisability above contextual understanding. By doing so, a FAIR-implementation is based on a number of implicit assumptions about data collection, use and reuse which complicate GO CHANGE activities. We will discuss two of those assumptions.

The first assumption is the notion that data collected within a specific context for a specific population (at this moment mainly, Western context) give a valid indicator of how, for example digital health data can be used to monitor and prevent diseases irrespective of the context and population at hand (the principle of generalisability within a positivistic paradigm, Neuman [16]). However, research has repeatedly indicated that this assumption is not valid [17, 18, 10]. This realisation calls for diverse research in terms of geographic context and participants involved (to get an indication of population generalisability [19]) and to investigate to what extent the indicators can be applied universally as a measure of the underlying theoretical construct that is used for risk prediction of diseases across global populations. This can be referred to as a parameter of the ecological validity [20].

In line with this argument, the methodologies and methods used to collect the data should be diverse to safeguard the validity of the data as an indicator of the underlying theoretical concept [21]. From this perspective, participation of African communities (scientific, policy makers and health users) is preemptory to enhancing the instrumentality of Digital Health data to serve practical solutions and services in Africa. GO FAIR assumes that generally more data means more knowledge. However, there are participants in the GO FAIR Africa Implementation Network who find that the data in the IFDS are – at present, not at all relevant for their context. The solution to this is to GO BUILD the IFDS in Africa. This will ensure that the FAIR principles are adapted to what is specific to African situations, which in turn will allow African data to be present in the IFDS.

Through GO CHANGE and GO BUILD simultaneously, the GO FAIR Implementation Network Africa needs to encourage participating members actively to engage with the principles and make them semantically and methodologically relevant to their data communities. In order for FAIR implementation in Africa to be relevant for academia and services at large, given needed investment of time, effort, connectivity and financial resources, it will be necessary to seriously increase the engagement with FAIR on the second largest continent in the world [3].

The second assumption concerns the idea that data should be gathered in a standardised, objective way to guarantee the reliability and validity of the data. Standardisation and an objective approach often overlook the fact that data are collected (and used) in real life in a social process with two kind of actors: the researchers and the participants. Both have their own idea of the goal of the research and how well that fits with their idea of the world. The researcher for example has specific beliefs about health (often

theories about health and well-being) as well as specific ideas about doing research (the dominant epistemology, favoured methodology, and research designs). These beliefs and opinions set the mode of conduct the researcher is applying in collecting and using data, with or without the help of a digital app and FAIR guidelines. An example is the fight against Ebola, where health researchers in protected outfits (as required by WHO standardised procedures) enter the problem areas, but are feared by the population, who are suspicious of western intentions, and believe the researchers have come to abduct them [22]. This demonstrates the (at times) uneasy relation between standard procedures, that seem entirely logical and the environment, producing unintended results. Araújo, Davids and Passos [20] identify this as representative design, which is a measure of the discrepancy between the research procedure and the natural environment. A representative design requires awareness of the specifics in a particular place: "proper sampling of situations and problems may in the end be more important than proper sampling of subjects, considering the fact that individuals are probably on the whole much more alike than are situations among one another" [23].

It can be recognised that data collection, use and reuse is always a social process taking place in a particular environment (as in symbolic interactionism, see for example Blumer [24]; Hewitt & Shulman [25], and ethnographic research, see for example Blommaert & Jie [26]; Hammersley [27]; Buskens & Van Reisen [28]). From this perspective the researcher and the design of the research are crucial for the way in which the environment appears within the outcomes. It is further important to understand that the actions taken by a researcher (or an application) prompt actions of the participant (such as complying or resisting the enforced way of doing, or not understanding what the researcher is doing, and why it should be done that way). These research dynamics themselves are an environment which have a considerable effect on the data gathered, their quality and henceforth the usefulness of the data to provide information about the phenomenon at hand. This can be referred to as "action fidelity" [29]; the degree in which the research situation may reflect or be transposed to the real situation. To overcome bias caused by the research situation itself there is need for incorporation of diverse epistemologies, methodologies, and research designs that not only fit the perspective of the researcher (and the corresponding research community), but also the perspectives of the participants and their corresponding community. If such situational aspects are recorded, IFDS can help achieve greater contextual understanding, through the rich metadata and provenance recommendations in the FAIR principles.

Finally, it should be recognised that the FAIR principles themselves form a research environment. Given the much greater distance in Africa between researchers, research participants and digital tools and data analytics, it can be assumed that the IFDS may have a larger distorting impact in an African research environment. This environment may be quite distant from an ordinary African setting and it may evoke reactions, emotions, interest, curiosity or rejection. In order to deal with the influence of FAIR Guidelines on the research process itself, some degree of data-generalisability can only be obtained if diverse environments are included fully in the inductive process of investigation with various degree of FAIRness. If FAIR Guidelines prompt a process that has little recognisability in an African setting, this affects the quality and validity of the data produced. To overcome this problem, the FAIR Guidelines should incorporate an

assessment of action fidelity between the artificial research situation and the natural situation. This recommendation corresponds fully with one of the suggested emerging practices of FAIR: a scrutiny by and involvement of citizens and general public in knowledge discovery which will democratise science and its use for services [2], implemented simultaneously in GO CHANGE and GO BUILD.

5. RECOMMENDATIONS REGARDING GO CHANGE: ENSURING ACCEPTANCE OF FAIR-IMPLEMENTATION OF DIGITAL HEALTH DATA IN AFRICA

According to Technology Acceptance Models (see for example, Venkatesh & Davis [30]) the perceived instrumentality of a technology as well as the perceived ease of use affect the acceptance by users of this technology. The perceived intentions of a FAIR-design and implementation also affect its acceptance.

The perceived instrumentality as well as the perceived ease of use are both affected by the ICT architecture (GO BUILD) of a FAIR-design and implementation of digital health data (in Africa) and the architecture of a technology evolves in social processes (socio-technical system [31, 32]). In building an application, people decide what characteristics of research (and data collection, use and reuse) are important to be incorporated [33] and how it should be implemented in FAIR (GO BUILD). By these man-made decisions, FAIR may be useful for specific purposes within a specific framework of doing research (the positivistic approach in a European setting). As indicated in the previous paragraph, FAIR is designed by a list of requirements in which the ecological validity, the representative design in context and the action fidelity are at present overlooked.

We see science as an innovative social process which explores the (different perceptions of) reality. From this perspective, science is dynamic and gives room for creativity and innovations and can hardly be forced into a one-size-fits-all strait-jacket [5]. Hence, GO BUILD implementation choices in Africa should explicitly take into account the diversity of research practices in the INs. The main activity of GO CHANGE is to inform participants about the FAIR implementation to identify its usability in their research practices and co-design it for best practice in specific contexts.

In order to advance FAIR in African health care, GO CHANGE should explicitly pay attention to the obstacles related to acceptance. The acceptance of FAIR by the African community is not only hindered by the lack of contextual understanding, the distance to digital connectivity and big data, but also by a feeling about the intentions of this European (Western) idea. The African community has a long history of dealing with European initiatives. Due to colonial history as well as more recent practices of Europeans in Africa, the African community regards Europeans as persons who extract and exploit from Africa (in this case: data) to store it elsewhere, out of reach of African communities [34]. Moreover, the data that are gathered in almost all current research in health is supported by actors from Europe or the US, who generally take the perspective of a Western worldview, corresponding to their needs and objectives. These approaches fail to take into account the African perspectives, objectives and epistemology [28]. Such practices may undermine acceptability of the good intentions of FAIR through response bias [35] and create resistance to FAIR as a worldwide repository which lacks value to the local context in Africa. Yet, this perceived asymmetrical

relationship between Africa and Europe is precisely what FAIR is aiming to resolve. In order to counteract any such feelings, it is of utmost importance that the African (scientific) community becomes a major player in the co-design, co-implementation and co-monitoring of the FAIR architecture for Africa.

6. TOWARDS AN AFRICAN IMPLEMENTATION OF FAIR: SYNERGY BETWEEN GO CHANGE AND GO BUILD

The danger that FAIR favours generalisability over contextual understanding, undermines attempts to develop a list of requirements to guide the design of the FAIR architecture avoiding a specific (European) objective, epistemology, methodology, or ideology. Furthermore, any design based on a list of requirements will feel as a strait jacket. Therefore, another approach to implementing FAIR is suggested, namely: design in practice (or design by doing) (see for example Gulliksen, Lantz & Boivie [36]). This design-approach, is frequently used in IT development, and is based on observations of the users' practices in the real world [36]. To implement FAIR in African digital health, is to start from the modes of conduct of doing research about health in Africa in general and digital health in particular. In this design approach, involvement of users is not only needed at the beginning and/or at the end of the design process, but throughout the (whole) process. Understanding of the ecological validity, situational representation and action fidelity should be assessed as part of this process: (i) an indication of context specificity, (ii) the inclusion of context variables in the research design and (iii) an assessment of the distance of the research procedure from a normal reality.

In the case of FAIR-implementation it means that GO CHANGE and GO BUILD are intertwined. By engaging African research communities in a FAIR Implementation Network Africa (FAIR IN Africa) the design of a FAIR-implementation of Digital Health can be undertaken with African ownership of the development and implementation, so that the likely bias towards the European research community is counterbalanced. Co-development and implementation of digital health within the principles of GO-FAIR, as proposed in the framework for GO FAIR IN Africa [37, 38, 39], can take into account the interconnectedness that is inherent in knowledge development and sharing that span single nation state borders and continents. This is a crucial consideration especially in an era of exponential growth and impact of digital technology at the global and local levels. It may mean that the FAIR architecture is never finished and will be constantly under construction and reconstruction.

AUTHOR CONTRIBUTIONS

M. van Reisen (mirjamvanreisen@gmail.com) guided the content of this article based on her research on the applicability of FAIR in Africa and the East Africa Community, providing feedback to other co-authors, final reviewing and editing of the article. M. Stokmans (M.J.W.Stokmans@uvt.nl) provided the theoretical underpinning of the article together with M. Mawere (munyaradzimawerem@gmail.com) who contributed largely on provisions of case studies in Zimbabwe, including examples and critiques from this perspective. M. Basajja (Mariam.basajja@gmail.com) carried out the literature review analysis of the data and reviewed

and edited the article. A. Ong'ayo (ongayo@iss.nl) contributed in the writing of several paragraphs with regards to the applicability of FAIR in the African context as well as feedback on other paragraphs. P. Nakazibwe (primrosenk@gmail.com) wrote reflections and paragraphs on acceptance of FAIR data by African communities. K. Chindoza (chindozak@gmail.com) reviewed and edited the article contributing technical understanding of the FAIR framework in Zimbabwe and its potential in an African context and worked on citations.

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